

## Congenital abnormalities and selective abortion

Mary J Seller *Paediatric Research Unit, The Prince Philip Research Laboratories, Guy's Hospital Medical School, London*

*The technique of amniocentesis, by which an abnormal fetus can be detected in utero, has brought a technological advance in medical science but attendant medical and moral problems. Dr Seller describes those congenital disabilities which can be detected in the fetus before birth, for which the 'remedy' is selective abortion. She then discusses the arguments for and against selective abortion, for the issue is not simple, even in the strictly genetic sense of attempting to ensure a population free of congenital abnormality.*

Once upon a time obstetricians merely had to deliver babies, now they are expected to deliver healthy babies. One reason for this is practical: nowadays medical care of an individual does not simply start around the time of birth but it begins early in his or her prenatal life. Another reason is that parents are tending to heed the call to curb the increase in the world population, so families are becoming smaller. If parents are actively limiting the size of their families then they want to ensure that the few children which they do have are as perfect and free from abnormality as possible. Then again, contemporary society as a whole now feels that it should be deeply concerned that any new member of it should be as normal and healthy as possible, so that he will not be a liability to that society, or to his parents, or to himself.

At the present time, about 6 per cent of all live-born children have some congenital abnormality (Polani, 1973) of which perhaps one half would be serious enough to render the children such a liability. The term 'congenital abnormality' covers a wide spectrum of disorders from developmental aberrations such as spina bifida to chromosomal errors such as Down's syndrome (mongolism), and point mutations which are responsible for the group of disorders known as 'inborn errors of metabolism'. In these diseases there is a disturbance in the biochemistry of the body which has profound and far-reaching repercussions on the mental and physical state. Within the last few years it has become possible to detect many of these abnormalities prenatally. However, this advance has not been matched by progress in the treatment of these disorders; there remain no remedies. So, the chosen course of action following detection is elimination by abortion. Thus a major ethical issue arises, Is abortion justified when a fetus is known to be abnormal?

Implicit in this is the basic question of the

morality of abortion. But there are deeper complexities surrounding the abortion of an abnormal fetus than those surrounding abortion in general. It is not simply that a life-or-death decision is involved, but that a quality judgment has to be made on the fetus. Because an abnormality is detected, someone has to assess the potentiality of this fetus and make the ultimate decision as to its fate. The inherent qualities, the nature and the attributes of the fetus form the pivot for the life-or-death decision; a judgment is made and somebody makes it. A human being actively intrudes and decides who of his fellow human beings shall live and who shall die, and furthermore, determines exactly what type of human being will live and what type shall die. It is these implications in the abortion of congenitally abnormal fetuses which transcend those raised by abortion in general.

### The range of congenital abnormalities

There are many problems inherent in a value judgment, none the least being defining what is normal, and then determining under what circumstances 'normal' can be considered to be normal. This is compounded by the heterogeneity of the term 'congenital abnormality' which encompasses a wide range of conditions from those where the abnormality is patently obvious to those which can only be regarded as 'borderline'. Four examples of disorders which can be detected prenatally will highlight this problem.

One of the most severe forms of congenital abnormality is anencephaly. The absence of a brain makes this condition incompatible with prolonged extrauterine life, and such an affected individual is clearly abnormal. Someone with a severe open spina bifida can survive if given good nursing care, but the quality of life experienced is usually poor when measured subjectively by healthy individuals. The victim has to face extensive and prolonged medical and surgical treatment and usually has severe physical handicaps such as paralysis of the lower limbs and incontinence and possibly mental handicap too. Individuals with Down's syndrome are severely mentally retarded, they are not capable of fending for themselves or of having an independent existence. However, if they are well cared for, they appear to have a reasonably happy life, but the burden of caring for them is quite large. The toll is not so much on the individual with the

congenital abnormality but more upon his family or society. Most males with a 47, XYY chromosome constitution (normal male: 46, XY) have no real handicap. They are phenotypically normal and the vast majority lead normal lives, and indeed, are not even aware that they have an extra chromosome. However, the condition does carry with it a small, but real, statistical probability of an unfavourable outcome. The 47, XYY individuals are unusually prone to pathological, antisocial behaviour, usually in the form of acts of criminal aggression leading to imprisonment. The statistical evidence is that while the incidence of such individuals in the newborn population is around 1 per 1000 males, the occurrence in penal populations is 20 per 1000 males (Hook, 1973). This is the dilemma; while an anencephalic is clearly abnormal, an individual with a 47, XYY karyotype is far from obviously abnormal.

### **Arguments for the selective abortion of the abnormal fetus**

For some people, the sanctity of life is paramount and under no circumstances is abortion acceptable. However, even some of the most vigorous opponents of abortion will concede that a justified exception may be made when the fetus is threatening the life of the mother, and so then a fetus may be aborted. Some people would extend this and view the abortion of a congenitally abnormal fetus in similar terms. They regard the abnormal fetus as an adversary against the life of the mother, inasmuch as her 'life' is constituted by her general wellbeing, which will be severely undermined by having to care for a handicapped child. Furthermore, the abnormal fetus threatens the wellbeing of other people too – the immediate family, the father and sibs, and society as a whole.

When the abortion of a congenitally abnormal fetus is considered there are clear and purposeful objectives. There is the ubiquitous aim of medicine: the elimination of suffering, both for the individual and for his family, and again, there is the preservation of precious medical and financial resources. These are serious and valid reasons, not merely the whims of social convenience. It is because of these that abortion in this context is considered by some as defensible. But if one can, in all conscience, reach such a decision, what does one do when confronted with the bewildering dilemma of discordant twins – the situation where one twin has a severe abnormality and the other is normal? This can, and does, arise, and it is not possible to abort one without the other.

In making a decision as to whether or not an abnormal fetus should be aborted, one really gauges the overall suffering and happiness which would be experienced by all involved, while at the same time bearing in mind the basic tenet of the sanctity of human life. It is generally believed that for a good

life happiness is the quintessence, and misery and suffering should be excluded. In the realms of prenatal diagnosis, these criteria are being used for making decisions about life and death. One is saying that to have a congenital abnormality will cause misery and suffering, and that the prevention of misery and suffering is more important than the preservation of life. But this is ostensibly contrary to perhaps our most fundamental moral tradition which is that it is wrong to take the life of a human. However, although everyone has a right to life, also included in our moral tradition is that there are certain circumstances when it is morally justifiable to take life. With new knowledge and new circumstances contemporary thinking tends to change, including concepts of what is morally correct. The recently introduced technique of prenatal diagnosis and selective abortion could well be one of these forces for change, for with it comes the emergence of a new right which is being accepted as validly overriding the right of an individual to life, that is, the right to be born free from a serious congenital abnormality.

It can be argued that by performing selective abortion man is merely expediting mother nature, for nature makes a definite statement about the fate of abnormal fetuses. A large number of pregnancies abort spontaneously – perhaps as many as 78 per cent (Roberts and Lowe, 1975), and a large proportion of these abortuses are abnormal; 60 per cent of them alone have chromosome anomalies (Boué, Boué and Lazar, 1975). It would seem, therefore, that nature intends to eliminate the seriously abnormal. Nature does make mistakes and aberrations arise but she has a system for eradicating these errors and this mechanism is abortion. If her selection procedure is faulty and she fails to detect all her mistakes, is not man justified in assisting her by using her very own system?

### **The long-term view of selective abortion of the abnormal fetus**

Some opponents of the abortion of the congenitally abnormal are concerned with the long-term view, and consider that the wider implications of its effect on the genetic constitution of the population as a whole are of utmost importance. This is particularly applicable to the disorders caused by point mutations, which have a predictable pattern of inheritance. An example is Tay-Sachs disease, which is caused by a mutant gene inherited as an autosomal recessive. There is progressive mental retardation, spasticity and blindness which relentlessly, over the course of time, lead to death. The occurrence of a child with this disorder implies that both parents are asymptomatic carriers of the mutant gene. In subsequent pregnancies they have a one in four chance of producing another affected child and three chances out of four of producing a child

without the disease. But of these three apparently normal children, two will be carriers of the mutant gene like their parents. With prenatal diagnosis, the affected child can be detected *in utero* and aborted, but the carriers will be born and live to pass on the deleterious gene to the next generation. Had the affected child been born, he would not have survived to reproduce, so the mutant gene would have been lost. Without prenatal diagnosis, his parents might not have had any more children because of the burden of caring for him and the risk of producing another affected like him. Instead, with prenatal diagnosis, they can embark on pregnancies confident of delivering only normal children. But since two out of three of these will be carriers, they are perpetuating the mutant gene. Thus, selective abortion in the long term will have the effect of altering the genetic constitution of the population, increasing the incidence of mutant genes. This demonstrates the fact that the health of society in general is dependent upon personal reproductive responsibility. But it is quite natural and understandable that a young couple who have produced a child with one of these tragic diseases will seek all the medical help they can for themselves to ensure that they have a normal child, without regard for the consequences which might ensue for future generations.

The prospective prevention of congenital abnormalities by selective abortion is not undertaken lightly by a profession which traditionally preserves life, however tenuous. It is recognized that it is by no means the ideal solution to a major problem, and research continues to seek remedies for the conditions involved so that abortion will not always be the concomitant of prenatal diagnosis. The present situation is regarded as a transient phase and selective abortion a temporary tool. It is a form of management and many individual cases have demonstrated that abortion is a satisfactory form of management for those primarily involved and that it can do far more good than harm.

There are some problems in life where solutions are available, but these solutions are inherently disagreeable. However, there are circumstances where it is feasible that one can actually be selected and implemented. Such an action may in itself violate the principle of the sanctity of life, but it can still be morally acceptable. Selective abortion following the prenatal diagnosis of congenital abnormalities could be one such circumstance.

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## Comment

Angus J McKay *Department of Moral Philosophy, University of Glasgow*

As Dr Seller points out, abortion in cases of abnormality raises questions which go beyond those normally associated with ethical discussion of the issue. However, some of the concepts used and arguments mentioned by Dr Seller do in fact relate to standard moral problems about abortion and indeed to other related issues such as euthanasia. For instance, reference is made on a number of occasions to notions such as 'the sanctity of life' and 'the right to life'. Ideas such as these need careful handling for a number of reasons.

In the first place, if we want to say that principles such as 'the sanctity of life' are relevant to debates about abortion either in normal or in abnormal cases (and I am not necessarily denying this), then we must be presupposing that at the fetal stage, or perhaps at some point in fetal development, it makes sense to regard the fetus as being a human being with a life which can be said to be in some sense its own life. And this issue, which is clearly related to questions such as, 'What is a human being or a person?' is one which, particularly in relation to the abortion debate, has been receiving considerable attention from moral philosophers recently. Just as medical experts and laymen have held widely divergent views about when and whether a fetus can be said to be a human being, so philosophers have argued for differing conclusions, some holding that a newly fertilized ovum is properly a human being, and others that we need not necessarily say of the emergent infant that he or she is a human being. Clearly then before we can settle the place of arguments concerned with the sanctity of life we must make up our minds about this prior issue. While this is not the time to give an extended discussion of this particular question it is worth reminding ourselves of its relevance both to Dr Seller's views and, as I have said, to the wider abortion debate.

A further point about the 'sanctity of life' argument emerges if we consider the contexts in which the author uses it. As she says, for some people such a principle rules out abortion in every case, while others regard such a principle as only one argument amongst others. The paper itself concludes that though abortion 'may in itself violate the principle

of the sanctity of life . . . it can still be morally acceptable'. Whether such a conclusion does follow will depend on just how we understand the notion of 'sanctity' here. If the sanctity of life means 'life ought never to be taken' and if the fetus is a human life, then such a principle does rule out abortion and Dr Seller's conclusion could not follow. If, however, sanctity means something less rigorous, what *does* it mean? Does it mean just that those concerned with such decisions as abortion ought to remember that they are dealing with human beings, which does not really give us any help in concrete decision making, or does it mean that in *some* circumstances abortion is ruled out because the taking of human life is not normally morally acceptable? If it means the latter, when does this principle cease to be the sole guiding principle? Dr Seller says that people making decisions about abortion of the abnormal fetus have to make judgments about 'the overall suffering and happiness which would be experienced by all concerned, while at the same time bearing in mind the basic tenet of the sanctity of human life'. Here it is worth noting that it is not an easy matter to see how to weigh against each other factors which are of rather different kinds. How do we decide how much suffering needs to be in view before we decide to violate a principle of the sanctity of human life? It seems to me that there may be something to be said for the view that it is in principle impossible to balance against each other factors which may be incommensurable; that if we do want to speak of the right to life of a fetus we are talking an altogether different kind of language from talk about the happiness or suffering which may well ensue. Thus it may be that what we really have to do, if we favour Dr Seller's approach, is to say that the issue is not really to be settled at all by reference to notions such as the sanctity of life.

Another relevant issue (as I am sure Dr Seller would agree) related to the preceding one is the importance of bearing in mind that while all of us do, often quite successfully, make forecasts about how much happiness or unhappiness possible courses of action will lead to for ourselves or for others, we may none the less be very imperfect judges of the extent to which even quite severely abnormal people may have a happy life. To say this is not of course to say that in any sense abnormalities must be considered to be a good thing, nor is it to ignore Dr Seller's point that there are some abnormal fetuses which have no chance whatever of surviving birth

by an appreciable length of time, or of surviving happily. On the other hand, we need to stress, as Dr Sellers does, that 'abnormality' covers a very wide range of conditions. To say that 'to have a congenital abnormality will cause misery and suffering' or that 'the abnormal fetus threatens the wellbeing of . . . the immediate family . . . and society as a whole' may encourage too easy an assumption that some disabled or abnormal lives must be worthless or too miserable for the individual concerned to bear. When we talk, for instance, of the misery which admittedly may be caused to parents, it is also important to recognize that what people may be prepared to put up with, and what indeed they may find fulfilment and happiness in, is something which is not easy to pin down or delimit in advance, but is something which varies enormously between individuals.

Finally, an argument used by Dr Seller which applies only to abortion in cases of abnormality, is the argument that selective abortion in such cases can be seen as helping nature to correct her own mistakes, since 'nature intends to eliminate the seriously abnormal'. Arguments such as this need to be used very carefully, and this is particularly true in the field of medicine. After all, if I can view spontaneous abortion as nature eliminating the abnormal, why cannot I also view cancer or any other disease as nature exhibiting an intention to eliminate a certain proportion of the population? Or, to take a case nearer to home, if we are justified in 'helping nature along' in general, what do we make of the common practice of attempting to forestall miscarriages in pregnant women, which are as much a part of 'nature' as any other process? A great deal of medicine is inevitably a matter of interfering with what is sometimes called nature's purposes. One underlying difficulty here is that it is not easy to attach a clear sense to the notion of nature's 'intentions'. If we say that nature intends what nature does, then not only spontaneous abortion but every other process, desirable or undesirable, becomes a part of nature's intentions. And if we say that nature's intentions are only a part of what nature does, how do we identify this part?

To raise such questions as the above is not necessarily to dispute the courses of action which Dr Seller favours, but rather to indicate areas in which those interested in the moral argument might look to clarify views which either support such courses, or indeed which go in other directions.